

ORIGINAL

BABY DOE...AND THE "NO-ANSWER SYNDROME"

By

C. EVERETT KOOP, M.D.

SURGEON GENERAL

U.S. PUBLIC HEALTH SERVICE

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



PRESENTED AT THE MILWAUKEE CHILDREN'S HOSPITAL OF
THE MEDICAL COLLEGE OF WISCONSIN
MILWAUKEE, WISCONSIN
AUGUST 9, 1984

(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I'M VERY PLEASED TO JOIN YOU THIS MORNING, AS PART OF THIS IMPORTANT SEMINAR ON "COPING WITH BABY DOE."

I'M JUST A COUPLE OF MONTHS SHY OF CELEBRATING MY THIRD ANNIVERSARY IN THE POSITION OF SURGEON GENERAL OF THE U.S. PUBLIC HEALTH SERVICE. DURING THOSE THREE YEARS A GREAT DEAL HAS HAPPENED IN SO MANY AREAS -- ORGAN TRANSPLANTS, "AIDS," THE DEVELOPMENT OF THE DIAGNOSIS RELATED GROUPS, OR D.R.G.s, AND SO ON -- BUT I DON'T THINK THERE HAS BEEN ANY AREA OF PUBLIC HEALTH POLICY THAT HAS STIMULATED SUCH WIDESPREAD DISCUSSION, SUCH CONFLICT -- INCLUDING LAWSUITS AGAINST THE GOVERNMENT -- AND SUCH PROFOUND CHANGE AS THIS AREA LABELLED "BABY DOE."

DR. BARTHEL'S GRACIOUS INVITATION TO ME SUGGESTED THAT I MIGHT WANT TO "SHARE THE 'NATIONAL' RESPONSE" TO THE CASE, AS EXPERIENCED BY YOUR OFFICE AND THE DEPARTMENT OF HEALTH AND HUMAN SERVICES." WHEN THAT LETTER ARRIVED LAST MAY, I REMEMBER I WAS IN A PARTICULARLY THOUGHTFUL MOOD AND I SAID TO MYSELF, "KOOP, THIS IS YOUR OPPORTUNITY TO PUT OUT ON THE RECORD WHAT YOU SAW...AND THOUGHT...AND FELT ABOUT THE 'BABY DOE' CASE."

SO I ACCEPTED THE INVITATION AND, AS DR. BARTHEL SUGGESTED, I'M GOING TO TRY TO CONVEY WHAT SOME OF US IN THE GOVERNMENT HAVE BEEN WORRYING ABOUT, EVERY SINCE THAT DAY IN APRIL 1982, WHEN LITTLE "BABY DOE" DIED IN BLOOMINGTON, INDIANA.

I AM CAREFUL TO SAY "SOME OF US IN THE GOVERNMENT" BECAUSE -- EVEN TODAY, AFTER MOST OF THE DUST HAS SETTLED -- THERE IS NOT COMPLETE AGREEMENT AS TO WHAT REALLY HAPPENED, WHAT IT ALL MEANS, AND WHAT WE HAVE TO DO NEXT. AND IN THIS RESPECT, I'M AFRAID THE GOVERNMENT ACCURATELY REFLECTS THE PROBLEM THAT IS ABROAD IN THE LAND GENERALLY.

BUT BEFORE I CONTINUE IN THIS VEIN, LET ME GO BACK IN TIME TO THE SPRING OF 1982, WHEN THIS ISSUE FIRST AROSE.

AS YOU ALL KNOW, "BABY DOE," OR "THE BLOOMINGTON BABY," AS THE LITTLE BOY WAS FIRST KNOWN, WAS BORN IN BLOOMINGTON HOSPITAL, INDIANA ON APRIL 8, 1982, WITH MULTIPLE CONGENITAL DEFECTS, INCLUDING AN ESOPHAGEAL OBSTRUCTION AND DOWN SYNDROME. AN ATTENDING SURGEON SAID THE OPERATIVE MORTALITY FOR CLEARING UP THE OBSTRUCTION WAS ABOUT 50 PERCENT. AN ATTENDING PEDIATRICIAN SAID THE INFANT WOULD GROW UP SEVERELY RETARDED.

MAKING THEIR DECISION ON THE BASIS OF THIS INFORMATION, THE PARENTS OF "BABY DOE" ASKED THAT NO FURTHER MEDICAL ASSISTANCE OR NOURISHMENT BE GIVEN TO THEIR CHILD.

BUT MEDICAL OPINION AT THE HOSPITAL WAS DIVIDED. IT'S IMPORTANT TO REMEMBER THAT FACT BECAUSE IT HAS BEEN ARGUED THAT THE POSITION TAKEN BY THE GOVERNMENT AND BY SOME CIVIL RIGHTS ADVOCATES IN THIS CASE HAS BEEN A POSITION AGAINST THE JUDGMENT OF PHYSICIANS. BUT THERE WAS NO SINGLE MEDICAL POSITION. FROM EVERYTHING WE NOW KNOW, HAD THERE BEEN A FORUM OF SOME KIND FOR DISCUSSION AMONG THE HOSPITAL'S PHYSICIANS, A MAJORITY MIGHT WELL HAVE OPPOSED THE PARENTS' DECISION.

FROM THE VERY BEGINNING, THE "BABY DOE" CASE HAD 2 SIDES TO ALMOST EVERY QUESTION THAT WAS RAISED...

2 SIDES AS TO WHAT THE TREATMENT OUGHT TO BE...

2 SIDES AS TO WHO MAKES SUCH DECISIONS...

2 SIDES AS TO HOW SUCH DECISIONS ARE MADE...

AND 2 SIDES IN REFERENCE TO WHICH PROCEDURES SHOULD BE FOLLOWED WHEN THERE IS NO CONSENSUS.

SOME OF THE PHYSICIANS AT BLOOMINGTON HOSPITAL, WHO DISAGREED WITH THE NEGATIVE OPINION OF THEIR COLLEAGUES AND THE DECISION OF THE PARENTS, WENT INTO COURT TO SEEK AN INJUNCTION PREVENTING THE PARENTS' DECISION FROM BEING CARRIED OUT AND, INSTEAD, REQUIRING THAT "BABY DOE" BE GIVEN SOME NOURISHMENT AND SOME MEDICAL CARE. THEIR AUTHORITY WAS THE INDIANA LAW ON CHILD ABUSE AND NEGLECT.

JUDGE JOHN BAKER, A CIRCUIT JUDGE SERVING MONROE COUNTY, HEARD TESTIMONY FROM BOTH SIDES -- EVEN HELD A LONG HEARING IN THE HOSPITAL ITSELF -- AND THEN RULED THAT NO INJUNCTION WAS NECESSARY. IN EFFECT, THE PARENTS WON THAT DECISION.

A SECOND CASE WAS BEGUN WHEN THE COUNTY PROSECUTOR'S OFFICE ENTERED WHAT IS KNOWN IN INDIANA AS A "CHINS" PETITION, THAT IS, A PETITION FOR A "CHILD IN NEED OF SERVICE." SUCH A PETITION IS USED ON BEHALF OF CHILDREN ALLEGED TO BE THE VICTIMS OF ABUSE OR NEGLECT.

THESE TWO CASES WERE IN THE JUDICIAL STREAM IN INDIANA. THE FIRST CASE, HEARD BY JUDGE BAKER, WAS APPEALED TO THE INDIANA SUPREME COURT. THAT COURT SAID THAT JUDGE BAKER HAD ACTED APPROPRIATELY AND HAD NOT EXCEEDED HIS AUTHORITY. THE INDIANA SUPREME COURT, HOWEVER, DID NOT REVIEW THE SUBSTANCE OF JUDGE BAKER'S DECISION. THE PLAINTIFFS -- PHYSICIANS OF BLOOMINGTON HOSPITAL -- APPEALED NEXT TO THE UNITED STATES SUPREME COURT.

ON APRIL 15, SEVEN DAYS AFTER HE HAD BEEN BORN, "BABY DOE" DIED. IN A MATTER OF HOURS, MR. JUSTICE JOHN PAUL STEVENS WAS TO HAVE HEARD A REQUEST THAT THE INDIANA SUPREME COURT DECISION BE OVER-RULED. BUT WITH THE BABY'S DEATH, THE REQUEST WAS MOOTED. THE SECOND CASE HAD THE SAME FATE. IT ALSO WAS MOOTED AT THE INDIANA APPELLATE LEVEL.

HENCE, EXCEPT FOR THAT FIRST TIME AROUND IN JUDGE BAKER'S COURT, THE SUBSTANCE OF THE "BABY DOE" ISSUE HAS NEVER BEEN THOROUGHLY ADJUDICATED...IN INDIANA, IN WASHINGTON, IN NEW YORK...ANYWHERE.

IT'S IMPORTANT TO REVIEW THIS INFORMATION BECAUSE ALL THE ELEMENTS OF THE "BABY DOE" CONTROVERSY OVER THE PAST 2 AND A HALF YEARS WERE RIGHT THERE IN THE ORIGINAL CASE. AND FOR THE NEXT SEVERAL MINUTES I WANT TO GO OVER THEM FOR YOU, FROM MY PERSPECTIVE...AS A SURGEON...AS A PHYSICIAN...AND AS SURGEON GENERAL.

FIRST, LET'S LOOK AT THE MEDICAL SIDE OF THIS ISSUE.

THE INITIAL DIAGNOSIS OF "BABY DOE" BY SOME OF THE BLOOMINGTON MEDICAL STAFF RAISED SOME EYEBROWS. WHILE IT IS TRUE THAT SURGERY TO REPAIR ESOPHAGEAL ATRESIA IN A NEWBORN CAN BE DIFFICULT AND TRICKY, IT IS ALSO TRUE THAT THE SUCCESS RATE IS VERY HIGH.

I WAS AMONG THE FIRST PEDIATRIC SURGEONS TO PERFORM CORRECTIVE SURGERY FOR ESOPHAGEAL ATRESIA. DURING MY 35 YEARS IN SURGERY I PERFORMED ABOUT 475 SUCH PROCEDURES WITH A HIGH SUCCESS RATE. IN THE LAST 7 YEARS OF MY EXPERIENCE, EVEN PREMATURE BABIES WITHOUT ADDITIONAL ANOMALIES, HAD A SURVIVAL RATE OF 88 PERCENT.

I GUESS IT WOULD BE NICE IF I COULD SAY I WAS UNIQUE...THAT SUCH A SUCCESS RATE WAS VERY MUCH OUT OF THE ORDINARY. BUT ACTUALLY IT ISN'T. THESE DAYS I WOULD SAY THAT MOST SURGEONS COULD EQUAL THAT RATE, OR COME PRETTY CLOSE. SO THE SURGICAL COMMUNITY HAD SOME LEGITIMATE QUESTIONS ABOUT THE VALIDITY OF THE SURGEON'S COUNSEL TO THE PARENTS OF "BABY DOE."

AND WE HAD TO QUESTION THE PEDIATRICIAN'S COUNSEL, ALSO. WE ARE GIVEN TO UNDERSTAND THAT THAT PERSON HAD INDICATED TO THE PARENTS THAT THE QUALITY OF "BABY DOE'S" FUTURE LIFE WOULD NOT BE VERY GOOD. THIS ALSO RAISED SOME EYEBROWS.

THERE IS SIMPLY NO WAY THAT A PHYSICIAN CAN PREDICT WITH ANY ACCURACY AT ALL JUST WHAT THE "QUALITY OF LIFE" WILL BE FOR A CHILD BORN WITH DOWN SYNDROME. THE SCALE OF RETARDATION CAN PASS FROM MILD TO SEVERE. AND AT EVERY POINT ON THAT SCALE, THE "QUALITY OF LIFE" IS AFFECTED BY THE CHILD'S FAMILY, THE RESPONSE OF THE COMMUNITY, AND THE KIND AND DEGREE OF MEDICAL AND HEALTH SERVICES THAT ARE AVAILABLE.

MOST OF YOU HERE THIS MORNING WOULD BE SUSPICIOUS OF A PHYSICIAN WHO MADE ANY FLAT PREDICTIONS ABOUT THE FUTURE "QUALITY OF LIFE" OF A PERSON RECOVERING FROM A BROKEN LEG, WHICH IS A FAR MORE TANGIBLE AND MEASUREABLE CONDITION THAN IS MENTAL RETARDATION.

SO THERE WERE QUESTIONS SURROUNDING THE KIND OF MEDICAL COUNSEL RECEIVED BY THE PARENTS OF "BABY DOE." SOME PEOPLE IN BLOOMINGTON, AS WELL AS SOME OF US WASHINGTON, THOUGHT THAT MAYBE THE PARENTS HADN'T BEEN GIVEN TOTALLY ACCURATE, BIAS-FREE, PROFESSIONALLY CONSERVATIVE INFORMATION ABOUT THE CONDITION OF THEIR NEW BABY BOY.

BUT SECOND, I THINK THE POINT MUST BE MADE -- AND EMPHASIZED -- THAT THOSE OF US IN WASHINGTON WHO WERE ASKED TO BECOME INVOLVED WERE RELUCTANT TO DO SO. SINCE THE MEDICAL RECORDS WERE SEALED BY THE COURTS, WE DID NOT HAVE AVAILABLE TO US ALL THE PERTINENT INFORMATION.

I WAS ASKED TO DO SOME LONG-DISTANCE HYPOTHESIZING ABOUT "BABY DOE'S" CHANCES, BUT I REFUSED. I BELIEVED THEN -- AND I GREW TO BELIEVE IT MORE INTENSELY LATER -- THAT THESE KINDS OF PROBLEMS CAN BE ANSWERED BEST BY CLEAR-THINKING, RESPONSIBLE PEOPLE WHO ARE RIGHT THERE ON THE SCENE.

AS IT TURNED OUT, WHEN "BABY DOE" DIED ON APRIL 15, 1982, A WEEK AFTER BIRTH, THE DEATH CERTIFICATE INDICATED "MULTIPLE CONGENITAL DEFECTS." BUT WHAT DID THIS MEAN?:

* WAS THERE IRREPARABLE HEART DAMAGE? NEARLY HALF OF ALL DOWN SYNDROME INFANTS ARE BORN WITH CONGENITAL HEART DISEASE AND THE MORTALITY RATES FOR SUCH INFANTS ARE VERY HIGH.

* WAS THERE IRREVERSIBLE BRAIN DAMAGE? THE MORTALITY RATE FOR ANENCEPHALICS IS 100 PERCENT. BUT FOR HYDROCEPHALICS, IT'S LESS THAN 10 PERCENT.

* OR WERE THE "MULTIPLE DEFECTS" ONLY THE 2 I HAVE ALREADY DISCUSSED...THAT IS, DOWN SYNDROME AND ESOPHAGEAL ATRESIA?

IN ANY CASE, THE PUBLIC DIDN'T HAVE ANY OF THIS INFORMATION BETWEEN APRIL 8 AND APRIL 15, 1982. WE DIDN'T HAVE IT THEN...AND WE STILL DON'T HAVE IT NOW.

THE MEDICAL PROFESSION WAS DOUBLY FRUSTRATED IN THIS CASE. FIRST, OF COURSE, THERE WAS THE LACK OF THE MEDICAL DATA. WE WERE THEORIZING IN THE DARK, WHICH IS REALLY ANATHEMA TO PHYSICIANS. WE'RE THE ONES WHO ARE ALWAYS CRITICIZED FOR WANTING TO KNOW TOO MUCH, FOR ORDERING TOO MANY TESTS AND TAKING TOO MANY X-RAYS AND SO ON.

THE REASONS FOR THIS ARE VARIED, BUT CHIEF AMONG THEM IS THE SIMPLE ONE OF THE PHYSICIAN'S DEEP DESIRE TO KNOW EVERYTHING ABOUT A CASE BEFORE RENDERING ANY OPINION. YET, MANY PHYSICIANS WERE TRYING TO FORM AN OPINION ON "BABY DOE'S" CHANCES...WITH ONLY THE BAREST INFORMATION AT HAND.

THE SECOND FRUSTRATION ALSO GOES RIGHT TO THE CORE OF MUCH OF CONTEMPORARY MEDICAL PRACTICE IS ALL ABOUT...FOR BETTER OR FOR WORSE. THE MEDICAL DEVELOPMENTS OF THE PAST 20 YEARS OR SO HAVE GREATLY EXPANDED THE RANGE OF CURATIVE MEDICINE, SO THAT WE BECOME ALMOST CATATONIC WHEN CONFRONTED BY A CASE THAT CANNOT BE CURED.

"BABY DOE" MADE THAT PART OF US ITCH. "BABY DOE" REMINDED US THAT FOR HIM...AS FOR MANY OF OUR PATIENTS...WE HAVE NO CURES. BUT WE CAN OFFER SOMETHING ELSE JUST AS VALUABLE. WE CAN OFFER SUCH PATIENTS A LOT OF GENUINE CARE. THEY MAY STILL NEED US AS PEOPLE, EVEN THOUGH WE CAN'T DO VERY MUCH FOR THEM AS PHYSICIANS.

THAT'S AN IMPORTANT MESSAGE. BUT IT'S A DEMANDING MESSAGE. IT DEMANDS THAT WE LAY ASIDE OUR MEDICAL TEXTS AND, INSTEAD, SIT DOWN AND WORK THROUGH THOSE QUESTIONS AND ANSWERS THAT ARE SPUN OUT OF THE DEPTHS OF OUR CONSCIENCE...NOT OUT OF MEDICAL TEXTS AND THE P.D.R.

LET ME CLARIFY A POINT HERE, IF YOU WILL. WHEN I SAY "WE," I'M REFERRING TO US, THE KNOWLEDGEABLE MEDICAL PROFESSION. AND, DESPITE THE LACK OF MUCH SPECIFIC INFORMATION, "WE" STILL HAD MORE EXPERTISE IN SUCH MATTERS THAN WAS DEMONSTRATED BY MOST OF THE NEWSPAPER WRITERS COVERING THIS CASE.

THEN THERE IS ALSO "WE" THE FEDERAL GOVERNMENT. BUT I SHOULD POINT OUT THAT "WE" IN GOVERNMENT WERE NOT INVOLVED IN THIS CASE UNTIL AFTER "BABY DOE" DIED.

IN MY PEDIATRIC SURGICAL PRACTICE I HAD COME UPON THIS KIND OF SITUATION BEFORE. NOT OFTEN..BUT ENOUGH TIMES SO THAT THE EXPERIENCE WAS ENGRAVED IN MY MIND FOREVER:

A TRAGICALLY DISABLED CHILD...PARENTS WHO ARE CONFUSED, ANGRY, GRIEVING...A DIVIDED MEDICAL STAFF. WHAT THEN?

MY CONSIDERED JUDGMENT -- WORKED OUT OVER SOME YEARS -- TELLS ME THAT WE OUGHT TO DO THOSE THINGS THAT GIVE A PERSON ALL THE LIFE TO WHICH HE OR SHE IS ENTITLED, BUT NOT DO ANYTHING THAT WOULD VAINLY EXTEND THAT PERSON'S ACT OF DYING.

THIS IS AN IMPORTANT PIECE OF THE PUZZLE, BECAUSE -- AND I'VE SAID THIS MANY TIMES BEFORE AND SINCE -- THERE IS A REAL DIFFERENCE BETWEEN GIVING A PERSON ALL THE LIFE TO WHICH HE OR SHE IS ENTITLED, AND PROLONGING THE ACT OF DYING.

WITH "BABY DOE," THERE WERE SO MANY FACETS TO DEAL WITH, EVEN IF THERE WAS NOTHING MORE TO THE DIAGNOSIS THAN WHAT WE LEARNED FROM THE NEWSPAPERS. ORAL INTAKE WAS IMPOSSIBLE BECAUSE OF THE ESOPHAGEAL LESION. PARENTERAL ALIMENTATION WOULD NOT SOLVE THE PROBLEM -- EVEN TEMPORARILY -- BECAUSE PULMONARY ASPIRATION OF PHARYNGEAL SECRETIONS AND OF GASTRIC JUICE THROUGH THE TRACHEO-ESOPHAGEAL FISTULA WOULD BE LETHAL.

THIS IS QUITE DIFFERENT FROM THE DECISION SOME ARRIVE AT, OF NOT TREATING AN OPEN MYELOMENINGOCELE, BUT FEEDING THE INFANT MEANWHILE.

THE THIRD ELEMENT IN THIS CASE -- AND THE LAST ONE I WILL HIGHLIGHT -- WAS THE FACT THAT "BABY DOE" DOES NOT FIT NEATLY INTO ANY OF OUR LEGAL PIGEONHOLES. THE FIRST ACTION WAS SIMPLY CALLED "IN THE MATTER OF 'BABY DOE'" AND WAS BROUGHT BY SOME OF THE MEDICAL STAFF AT BLOOMINGTON HOSPITAL. THE BASIS FOR THEIR ACTION, AS I'VE INDICATED, WAS THE INDIANA STATE LAW REGARDING CHILD ABUSE AND NEGLECT.

BUT THE "BABY DOE" CIRCUMSTANCES WERE DIFFERENT. THIS WAS NOT A STRAIGHTFORWARD CASE OF CHILD ABUSE AND NEGLECT, IN WHICH A NORMAL, HEALTHY CHILD IS THE VICTIM OF PARENTAL VIOLENCE.

NO ONE DID ANYTHING "VIOLENT" TO "BABY DOE." NO ONE MOVED TO HELP HIM, BUT NO ONE LIFTED A FINGER AGAINST HIM EITHER. HE WASN'T DRIVEN OUT OF THE HOUSE INTO THE COLD, BLACK NIGHT. IN ADDITION, "BABY DOE" HIMSELF WAS NOT THE NORMAL, HEALTHY CHILD THAT PEOPLE EASILY SEE IN THEIR MIND'S EYE.

THE KEY TO THIS CASE, THEN, WAS THE CHILD'S HANDICAPPING CONDITION. THIS IS WHAT MADE IT NEWSWORTHY...WHAT MADE THE CIRCUMSTANCES PARTICULARLY TROUBLING...AND WHAT STIMULATED A NUMBER OF PEOPLE IN INDIANA, ELSEWHERE IN THE COUNTRY, AND IN WASHINGTON TO THINK ABOUT "BABY DOE" AS A VICTIM OF DISCRIMINATION INSTEAD OF -- OR IN ADDITION TO -- BEING A VICTIM OF ABUSE AND NEGLECT.

NOW WE HAD TO ASK IF THE CARE BEING GIVEN TO "BABY DOE" WAS THE KIND OF CARE ANY BABY WITH ESOPHAGEAL ATRESIA WOULD RECEIVE? MANY PEOPLE THOUGHT NOT. THE ASSOCIATED DOWN SYNDROME WAS, THEREFORE, EXTREMELY SIGNIFICANT. HAD "BABY DOE" HAD ONLY DOWN SYNDROME, HE WOULD HAVE BEEN NOURISHED AND CARED FOR. HAD HE HAD ONLY ESOPHAGEAL ATRESIA, HE WOULD HAVE BEEN OPERATED ON AND CURED.

EVENTUALLY THE ARGUMENT CENTERED AROUND SECTION 504 OF THE REHABILITATION ACT OF 1973, OR PUBLIC LAW 93-112. THAT SECTION SAYS THAT "NO OTHERWISE QUALIFIED HANDICAPPED INDIVIDUAL...SHALL, SOLELY BY REASON OF HIS HANDICAP, BE EXCLUDED FROM THE PARTICIPATION IN, BE DENIED THE BENEFITS OF, OR BE SUBJECTED TO DISCRIMINATION UNDER ANY PROGRAM OR ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE."

THIS IS ALMOST IDENTICAL TO THE LANGUAGE OF TITLE VI OF THE CIVIL RIGHTS ACT OF 1964 AND OF TITLE IX OF THE EDUCATION AMENDMENTS OF 1972. AS YOU KNOW, THOSE TWO LAWS FORBID ANYONE USING FEDERAL FUNDS FROM DENYING BENEFITS OR SERVICES TO A BLACK PERSON BECAUSE HE OR SHE IS BLACK...OR AN HISPANIC PERSON...OR AN ASIAN...OR AN ELDERLY PERSON...OR A WOMAN.

LIKE MOST MAJOR HOSPITALS IN THE COUNTRY, BLOOMINGTON HOSPITAL DID AND DOES RECEIVE FEDERAL ASSISTANCE AND, THEREFORE, MUST CONDUCT ITS AFFAIRS ACCORDING TO A NUMBER OF FEDERAL LAWS, INCLUDING TITLE VI, TITLE IX, AND SECTION 504.

IRONICALLY, WHILE THERE WERE FEDERAL REGULATIONS ON THE BOOKS WITH WHICH TO ENFORCE TITLES VI AND IX, THERE WERE STILL NO REGULATIONS FOR ENFORCING SECTION 504. THE ISSUES HAD BEEN WELL DISCUSSED DURING THE CONGRESSIONAL DEBATES OF 1972, '73, AND '74. AND THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE -- AS WE WERE THEN KNOWN -- HAD PROPOSED SOME DRAFT RULES IN 1976 AND 1977, BUT HAD JUST NEVER GOT AROUND TO PUTTING OUT FINAL REGULATIONS.

HOWEVER, RELYING ON THE PUBLIC RECORD OF THE PREVIOUS 10 YEARS AND THE WIDESPREAD PUBLIC INTEREST IN THE LIFE OF THE BLOOMINGTON BABY, THIS ADMINISTRATION DECIDED TO MOVE AHEAD WITH THE ENFORCEMENT REGULATIONS REQUIRED BY SECTION 504.

BUT I DO WANT TO AT LEAST MENTION ONE OTHER MATTER OF LAW THAT CAME UP EARLY IN THE HISTORY OF "BABY DOE." AND IT REMAINS AS AN ISSUE FOR MANY PEOPLE. BRIEFLY STATED, IT IS THIS: DOES THE STATE HAVE ANY BUSINESS AT ALL TO STEP INTO A MATTER AFFECTING A NEWBORN CHILD AND GO OVER THE HEADS, SO TO SPEAK, OF THE PARENTS?

AS YOU KNOW, WHEN THE "BABY DOE" CASE FIRST HIT THE NEWSPAPERS, A NUMBER OF PEOPLE SAID THE GOVERNMENT "HAD NO RIGHT" TO INTERFERE IN A MATTER THAT WAS THE RESPONSIBILITY ONLY OF THE PARENTS AND OF THE ATTENDING PHYSICIANS. EVERYONE KNOWS THERE ARE TRUANCY LAWS AND CHILD ABUSE LAWS AND IMMUNIZATION LAWS AND SO ON, WHERE THE STATE'S RIGHT TO INTERFERE IS NEVER SERIOUSLY CHALLENGED. THOSE LAWS SEEM TO BE ACCEPTED MAINLY BECAUSE, FOR THE MOST PART, THEY CONCERN CHILDREN WHO ARE NO LONGER INFANTS.

IF THE "BABY DOES" OF THIS WORLD WERE 35 YEARS OLD, THEY OWULD HAVE A NATIONAL ADVOCACY ORGANIZATION AND A STRONG CONGRESSIONAL LOBBY. UNFORTUNATELY THEY ARE TOO SMALL, TOO WEAK, AND TOO POOR.

THERE IS NO CONSTITUTIONAL DEFINITION OF HOW OLD SOMEONE HAS TO BE IN ORDER TO RECEIVE THE PROTECTION OF THE STATE. THERE IS NO MINIMUM-AGE REQUIREMENT FOR NATIVE-BORN CITIZENSHIP. FOR EXAMPLE, AN AMERICAN-BORN CHILD DOES NOT HAVE TO REMAIN IN THE UNITED STATES FOR A MONTH...OR TWO WEEKS...OR EVEN FOR ONE HOUR IN ORDER TO QUALIFY -- 35 YEARS LATER -- TO RUN FOR PRESIDENT. THE CHILD MERELY HAS TO BE "BORN" AS AN AMERICAN.

I DON'T FIND THAT DIFFICULT TO UNDERSTAND. I NEVER DID. AND, FOLLOWING THAT SAME LOGIC, I BELIEVE THAT A NEWBORN INFANT WHOSE LIFE IS PUT AT RISK BY A PARENT, A GUARDIAN, A PHYSICIAN, OR BY WHOMEVER -- I BELIEVE THAT CHILD IS A CITIZEN AND DESERVES TO BE ACCORDED THE FULL PROTECTION OF THE STATE.

"BABY DOE'S" LIFE BEGAN WITH MANY TRAGIC COMPLICATIONS. BUT NONE OF THOSE HANDICAPS PUT HIM OUTSIDE THE PROTECTION OF THE LAW. NONE OF THEM RELIEVED THE STATE OF ITS OBLIGATION TO PROTECT HIM. NONE OF THEM PERMITTED ANYONE TO FURTHER JEOPARDIZE HIS HEALTH OR HIS LIFE. NONE OF THEM.

I'VE TALKED ENOUGH ABOUT THE LEGAL ASPECTS OF "BABY DOE" AND SO I WON'T RECOUNT ALL THE COURTROOM MANEUVERS OF THE PAST YEAR. ALSO, A FEDERAL COURT HAS ENJOINED OUR DEPARTMENT FROM CARRYING OUT ITS SECTION 504, OR "BABY DOE," REGULATIONS, PENDING THE OUTCOME OF THE LATEST LAWSUIT AGAINST US. UNTIL THAT CASE CLEARS THE 2ND U.S. CIRCUIT COURT OF APPEALS, IT WOULD BE INAPPROPRIATE FOR ME TO DISCUSS OR COMMENT ON THE LEGAL ARGUMENTS OF EITHER SIDE.

HOWEVER, THE ETHICAL ISSUES REMAIN, AND THEY'VE SHOWN LIKE SPOTLIGHTS, REVEALING SHARP DIVISIONS WITHIN THE MEDICAL COMMUNITY. PHYSICIANS -- LIKE THE REST OF AMERICANS -- ARE DEEPLY TROUBLED BY "BABY DOE" AND ARE UNSURE OF WHAT THEIR POSITION SHOULD BE. ALTHOUGH OUR DEPARTMENT HAS BEEN SUED BY DIFFERENT PHYSICIANS' ORGANIZATIONS, I THINK IT IS CLEAR THAT THERE IS NO SINGLE POSITION THAT CAN BE LABELLED AS REPRESENTING THE THINKING OF "ORGANIZED MEDICINE."

BACK IN 1977, THE JOURNAL OF PEDIATRICS PUBLISHED A SURVEY MADE OF TWO GROUPS: ONE, THE 400-MEMBER SURGERY SECTION OF THE AMERICAN ACADEMY OF PEDIATRICS; THE OTHER, A GROUP OF 300 PERSONS WHO CHAIRED DEPARTMENTS OR DIVISIONS OF PEDIATRICS, NEONATOLOGY, AND GENETICS. THEY WERE ASKED A SERIES OF QUESTIONS THAT READ ALMOST LIKE A FRIEND-OF-THE-COURT BRIEF IN "BABY DOE" -- BUT, OF COURSE, 5 YEARS EARLIER.

FOR EXAMPLE...

THEY WERE ASKED, "WOULD YOU ACQUIESCE IN THE PARENTS' DECISION TO REFUSE CONSENT FOR SURGERY IN A NEWBORN WITH INTESTINAL ATRESIA IF THE INFANT ALSO HAD DOWN SYNDROME ALONE?" AMONG THE SURGEONS, 77 PERCENT WOULD HAVE ACQUIESCED, 19 PERCENT WOULD NOT. BUT THE PEDIATRIC GROUP SPLIT ON THE QUESTION...HALF SAID THEY WOULD AND HALF SAID THEY WOULDN'T.

WHAT IF THE PARENTS DECIDED THAT THEY DID NOT WANT ANY CORRECTIVE SURGERY DONE? 63 PERCENT OF THE SURGEONS SAID THEY WOULD THEN STOP ALL SUPPORTIVE TREATMENT; 31 PERCENT SAID THEY WOULD CONTINUE TO AT LEAST GIVE ORAL FEEDINGS. HOWEVER, ONLY 43 PERCENT OF THE PEDIATRIC GROUP WOULD STOP ALL SUPPORTIVE TREATMENT...BUT THEY WERE GENERALLY UNSURE ABOUT WHAT THEY WOULD DO INSTEAD. ONLY 18 PERCENT WOULD GIVE ORAL FEEDINGS.

BUT BY FAR THE LARGEST NUMBER OF RESPONSES TO THIS AND SIMILAR QUESTIONS FELL INTO THE "NO ANSWER" COLUMN.

SEVEN YEARS HAVE PASSED SINCE THAT SURVEY WAS PUBLISHED. TODAY, WE CAN NO LONGER ACCEPT "NO ANSWER"...AS AN ANSWER. NOT FROM PEDIATRICIANS...NOT FROM SURGEONS...NOT FROM THE GOVERNMENT...AND NOT FROM THE PUBLIC. IF CONFRONTED BY A NEWBORN INFANT WITH ONE OR MORE DISABLING CONDITIONS, EACH ONE OF US MUST BE PREPARED TO RESPOND -- NOT BEG OFF AND WALK AWAY.

AND THAT'S THE ETHICAL ISSUE WE'VE GOT TO DEAL WITH. I CALL IT THE "NO-ANSWER SYNDROME."

"BABY DOE" WAS A TINY BABY BOY WITH "MULTIPLE CONGENITAL DEFECTS." YET, THAT CHILD HAS FIGURATIVELY TAKEN AMERICA BY THE SHOULDERS AND HAS GIVEN US A GOOD SHAKE.

"BABY DOE" ASKS US TO CONFESS HOW WE REALLY FEEL ABOUT OUR FELLOW HUMAN BEINGS.

"BABY DOE" PRODS US INTO REVEALING WHETHER WE ARE -- OR ARE NOT -- THE FRIENDS OF THE HELPLESS, THE WEAK, THE HURT, THE INJURED, AND THE TROUBLED.

"BABY DOE" HAS LITTLE PATIENCE FOR RHETORIC AND THEORY...WILL NOT STAND FOR ARGUMENTS TO DEFEND SOME PERCEIVED THREATS TO SELF-INTEREST ...AND "BABY DOE" WILL NOT PATIENTLY WAIT IN THE BACKGROUND WHILE THE INSTITUTIONS OF MEDICINE AND LAW AND RELIGION AND GOVERNMENT FIGHT FOR SOME TEMPORARY PRIMACY.

UNTIL "BABY DOE" CAME ALONG, IT WAS ACCEPTABLE -- AND EVEN FASHIONABLE -- TO PROCLAIM ONE'S ALLEGIANCE TO THE THEORETICAL PRINCIPLE OF THE SANCTITY OF EVERY HUMAN LIFE.

BUT THEN THIS LITTLE LIFE APPEARED. AND HE JUST WASN'T VERY PRETTY.

HE MADE IT DIFFICULT FOR PEOPLE TO LOVE HIM. YOU HAD TO BE STRONG TO WANT TO HOLD HIM AND TO CUDDLE HIM.

HE WAS THE KIND OF INFANT THAT IS VERY EXPENSIVE TO CARE FOR -- EVEN THOUGH NOBODY HAS YET DARED TO FIGURE OUT WHAT THE FINANCIAL "BOTTOM LINE" IS FOR SUCH CARE.

HE WAS NOT JUST A PROFOUND MORAL AND ETHICAL CHALLENGE TO HIS PARENTS AND TO THE MEDICAL STAFF OF BLOOMINGTON HOSPITAL. HE CHALLENGED US ALL.

DURING THE PAST COUPLE OF YEARS -- IN BOTH MY PERSONAL AND MY PROFESSIONAL CAPACITIES -- I HAVE HAD TO WRESTLE WITH THE ETHICAL PROBLEMS RAISED BY THE SUFFERING OF A SPECIFIC HUMAN BEING...DR. BARNEY CLARK IN UTAH, FOR EXAMPLE...AND THE LITTLE CHILDREN WHO HAVE NEEDED LIVER TRANSPLANTS TO SURVIVE. DEATH FOR THEM WAS IMMINENT, BUT WE WERE DOING OUR BEST TO KEEP THEM ALIVE.

THEN THERE WAS THE LITTLE BOY CALLED "BABY DOE," WHOSE DEATH WAS ALSO IMMINENT...WHO WAS NOT BEING KEPT ALIVE...AND FOR WHOM MANY PEOPLE IN MEDICINE COULD MUSTER NOTHING BETTER THAN THE "NO-ANSWER SYNDROME."

SOMETIMES THE ETHICAL PROBLEM IS JUST AS POWERFUL, DESPITE THE FACT THAT THE SPECIFIC HUMAN BEING WHO COMES TO MIND HAS LONG SINCE DIED. SUCH WAS THE CASE LAST YEAR, WHEN I WAS ASKED TO KEYNOTE A MEETING IN NEW YORK THAT WAS TO FOCUS ON THE "BYSTANDER SYNDROME." THE MEETING WAS HELD ON THE 20TH ANNIVERSARY OF THE MURDER OF MISS CATHERINE -- "KITTY" -- GENOVESE, A YOUNG WOMAN WHO WAS BRUTALLY STABBED BY A MAN, BUT WAS LEFT TO DIE BY 35 PEOPLE WHO HEARD HER SCREAM...BUT WHO "DIDN'T WANT TO GET INVOLVED."

THE IRONY IS THAT THOSE 35 BYSTANDERS -- AND HUNDREDS AND THOUSANDS OF OTHERS THEN AND SINCE -- REMAIN INVOLVED IN THAT MURDER. AND WE ASK OURSELVES THE SAME QUESTIONS OVER AND OVER AGAIN:

"WHY DIDN'T I...?"

"WHY WOULDN'T I...?"

AND "WILL I...?"

"BABY DOE" IS EVERY BIT AS INSISTENT AS IS THE GHOST OF KITTY GENOVESE. AND HE PROMPTS THE SAME QUESTIONS:

"WHY DIDN'T I STAND UP FOR THAT CHILD?"

"WHY WOULDN'T I DEFEND HIS RIGHT TO PROTECTION UNDER THE LAW?"

AND "WILL I RISE TO DEFEND THE NEXT ONE?"

I CERTAINLY PREFER EDUCATION TO REGULATION. I TRIED THE EDUCATIONAL TASK FOR 35 YEARS IN ACADEMIA. MOST OF WHAT I TAUGHT IN MY SPECIALITY OF PEDIATRIC SURGERY HAS BEEN ACCEPTED AS COMMON PRACTICE TODAY. ONE CONCEPT I REPEATED OVER AND OVER AGAIN CAUGHT HOLD IN THE YEARS 1947 THROUGH 1967, BUT THEN BEGAN TO FADE. THIS WAS THE IDEA THAT YOUNGSTERS BORN WITH CONGENITAL ANOMALIES COULD BE AGGRESSIVELY TREATED...THAT THE COMMUNITY SUPPORT SYSTEMS EXISTED TO HELP THEM...AND THAT THE ROLE OF PARENTAL LOVE COULD DO FAR MORE THAN THE PESSIMISTIC ASSUMPTIONS OF MANY PHYSICIANS.

BUT SOMETIME AFTER 1967 THE "QUALITY OF LIFE" ETHIC OVERTOOK THE TRADITIONAL "EQUALITY OF LIFE" ETHIC HANDED DOWN BY HIPPOCRATES. AND THEN INFANTICIDE NOT ONLY OCCURRED BUT WAS OPENLY SUPPORTED AND WENT UNCHECKED FOR THE MOST PART AND CERTAINLY UNQUESTIONED.

IF I AM ANY JUDGE, I THINK -- ODDLY ENOUGH -- THAT IT "PEAKED OUT" AND BEGAN TO DECLINE BEFORE "BABY DOE" ARRIVED IN BLOOMINGTON.

I MUST CONFESS TO A CERTAIN AMOUNT OF CHAGRIN THAT MY EDUCATIONAL EFFORT WAS NOT MORE SUCCESSFUL. SO WHEN THE TIME CAME, I CONTRIBUTED MY EFFORTS, SOMEWHAT RELUCTANTLY, TO THE DEVELOPMENT OF "BABY DOE" REGULATIONS. IN THE FINAL RULE -- THE ONLY ONE I WROTE -- I DID SUGGEST A PLAN THAT WAS WORKABLE, AT LEAST IN THE JUDGMENT OF THE DISABILITY GROUPS AND THE AMERICAN ACADEMY OF PEDIATRICS AND THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS.

BUT, AS I MENTIONED A MOMENT AGO, THE GOVERNMENT HAS BEEN ENJOINED FROM CARRYING OUT ITS REGULATIONS TO PROTECT THE "BABY DOES" OF THE FUTURE UNDER SECTION 504 OF THE REHABILITATION ACT. HOWEVER, THE U.S. CONGRESS WANTS TO PROTECT SUCH "BABY DOES" BY REVISING THE CHILD ABUSE AND NEGLECT LAW.

I THINK WE IN THE EXECUTIVE BRANCH WERE RIGHT IN OUR APPROACH TO THE PROBLEM. BUT IF IT DOESN'T WORK, THEN I WOULD PROBABLY AGREE THAT THE CONGRESS MAY BE RIGHT IN ITS APPROACH.

AS YOU CAN SEE, I'M NOT AN ATTORNEY AND SO THE LEGAL NICETIES AND SUBTLETIES ESCAPE ME. BUT I CAN SEE THAT, WHEN EDUCATION FAILED, REGULATION BECAME NECESSARY. AND WHEN THAT PROCESS WAS ENJOINED BY THE COURTS, THEN CONGRESS -- MINDFUL OF THE CONSTITUTIONAL MANDATE FOR EQUAL PROTECTION UNDER THE LAW -- HAS FOUND IT NECESSARY TO TURN TO SPECIFIC "BABY DOE" LEGISLATION.

I DO BELIEVE OUR APPROACH IN THE EXECUTIVE BRANCH WOULD BE ALL RIGHT -- PROVIDED THE MEDICAL COMMUNITY AND THE PUBLIC DECIDED TO CHOOSE THE LIFE OPTION FOR HANDICAPPED CHILDREN.

AND I'M SURE THE APPROACH OF THE CONGRESS COULD WORK, TOO -- IF PHYSICIANS AND SURGEONS AND MOTHERS AND FATHERS AGREED THAT THEY WOULD NOT MAKE LIFE-OR-DEATH DECISIONS ON THE BASIS OF WHAT IS GOOD OR CONVENIENT OR FINANCIALLY FEASIBLE FOR THEM BUT, RATHER, WHAT IS THE ETHICAL IMPERATIVE ON BEHALF OF A DISABLED INFANT IN THEIR CARE.

YOU SEE, WHEN WE SAY, "'BABY DOE' HAS A LIFE THAT'S NOT WORTH LIVING," ARE WE NOT REALLY SAYING, "IT'S NOT WORTH OUR EFFORT TO CARE FOR HIM"?

I ABSOLUTELY BELIEVE THAT WE WOULD NOT BE HERE TODAY...THERE WOULD BE NO CONFERENCE ON "COPING WITH 'BABY DOE'"...THERE WOULD BE NO LAWSUIT AND NO PENDING LEGISLATION, IF OUR SOCIETY HAD REMAINED TRUE TO ITS MORAL AND ETHICAL ROOTS...THAT IS, IF IT RE-COMMITTED ITSELF TO THE PRESERVATION AND THE PROTECTION OF THE RIGHTS OF EVERY HUMAN BEING, NO MATTER HOW LOW OF STATION OR YOUNG OF AGE.

IT'S POSSIBLE THAT WE'VE STRAYED FROM THAT PATH. BUT WE'VE GOT TO RETURN TO IT AS SOON AS WE CAN. FOR WITHOUT THAT KIND OF RESOLUTION, WE REMAIN PRONE TO COMMITTING TRAGIC ERRORS IN SUCH ENDEAVORS AS MAJOR ORGAN TRANSPLANTATION, HEALTH CARE FOR OUR ELDERLY, THE DETECTION AND TREATMENT OF CANCER, AND THE IMPROVEMENT OF ENVIRONMENTAL AND OCCUPATIONAL HEALTH.

IN CLOSING, LET ME REPEAT SOME WORDS WRITTEN JUST A FEW YEARS AGO BY THE LATE RENE DUBOS, A GREAT SCIENTIST AND A GREAT HUMAN BEING. THEY ARE IN HIS BOOK, TITLED CELEBRATIONS OF LIFE. DR. DUBOS SAID...

"...SCIENTISTS COMMONLY OVERESTIMATE THE EXPLANATORY VALUE OF SCIENTIFIC KNOWLEDGE. THEY SEEM TO SUFFER FROM A KIND OF PAROCHIALISM COMMON AMONG SPECIALISTS, NAMELY THE BELIEF THAT HUMAN LIFE CAN BEST BE EXPLAINED BY THE PHENOMENA STUDIED IN THEIR OWN PROFESSIONAL SPECIALTY. HUMAN NATURE, HOWEVER, IS NOT SO SIMPLE..."

ND HE WENT ON TO SAY THAT...

"IT IS BECAUSE WE ARE GENETICALLY ENDOWED WITH THE ABILITY TO IMAGINE, TO SYMBOLIZE, TO ANTICIPATE THE FUTURE AND TO CHOOSE AMONG OPTIONS THAT WE CAN CREATE THE PHYSICAL AND CONCEPTUAL ENVIRONMENTS IN WHICH WE SPEND OUR LIVES."

IN OTHER WORDS, EACH ONE OF US IS CAPABLE OF NOT ONLY EXPERIENCING -- BUT ALSO RISING ABOVE -- THE CONDITIONS OF DAILY LIFE, AS THEY ARE EXPLAINED BY PEDIATRICIANS AND LAWYERS AND CERTIFIED PUBLIC ACCCOUNTANTS. THE WORLD CAN BE BETTER FOR US AND FOR EVERY CHILD THAT ENTERS IT. WE HAVE TO REJECT THE "NO-ANSWER SYNDROME" AND CONSCIOUSLY CHOOSE THE LIFE-GIVING OPTION.

I FERVENTLY HOPE THAT WE DO.

OUR LIVES -- AS HEALTH PROFESSIONALS -- AND THE LIVES OF THE PARENTS AND THE DISABLED ARE REMARKABLY SHAPED BY THE CARE WE GIVE THE HANDICAPPED. I THINK MY 40 YEARS OF HANDS-ON EXPERIENCE HAS CONVINCED ME THAT ALL APSECTS OF MEDICAL ETHICS ARE DWARFED BY THE QUESTION:

"HOW OUGHT WE TO CARE FOR THOSE WHO CANNOT -- IN ONE WAY OR IN EVERY WAY -- CARE FOR THEMSELVES?"

WHEN WE'VE SETTLED THAT QUESTION, THEN WE CAN TURN TO THE OTHERS...FINANCES, RESOURCES, COMMITTEES, AND SO ON.

NO ONE SAID IT WOULD BE EASY. I'M NOT EVEN SAYING IT CAN BE OBJECTIVE. WHAT I AM SAYING IS THAT THE QUALITY OF LIFE WE TALK SO MUCH ABOUT IS NOWHERE AS IMPORTANT AS IN THE REFLECTION THESE DECISIONS MAKE IN THE QUALITY OF OUR OWN LIVES.

THANK YOU.

#